SNSF IICT 2026 application: How to successfully address the PPI requirements

Online course on patient and public involvement (PPI)

3 MARCH 2026, 16:00-18:00

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Information

- Please mute your microphone when you are not speaking
- We have dedicated Q&A sessions where questions will be addressed at the end of each presentation
- Please write your questions in the chat or raise your hand via Zoom.
- This course is recorded. The recording (excluding the Q&A session) will be published on the SCTO website after the course
- Feel free to turn off your camera during the presentations

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PROGRAMME AGENDA

ORDER	TOPIC	TIME
01	Introduction to PPI, Sabine Rütti Roch	16:00
02	PPI in practice, Cindy Allenbach & Marie Méan	16:15
03	Break	16:45
04	Useful information for applicants, Caroline Krüger & Larisa Aragon	17:00
05	PPI in the IICT call & Clinical Research Centre (CRC) support, Sandra Kohlmaier	17:20
06	Q&A	17:40

Objectives

- Understand the PPI concept
- Translate PPI principles to your study/project
- Create a plan for PPI
- Recognise the value of Clinical Research Centres (CRCs) as a partner
- Apply the PPI requirements

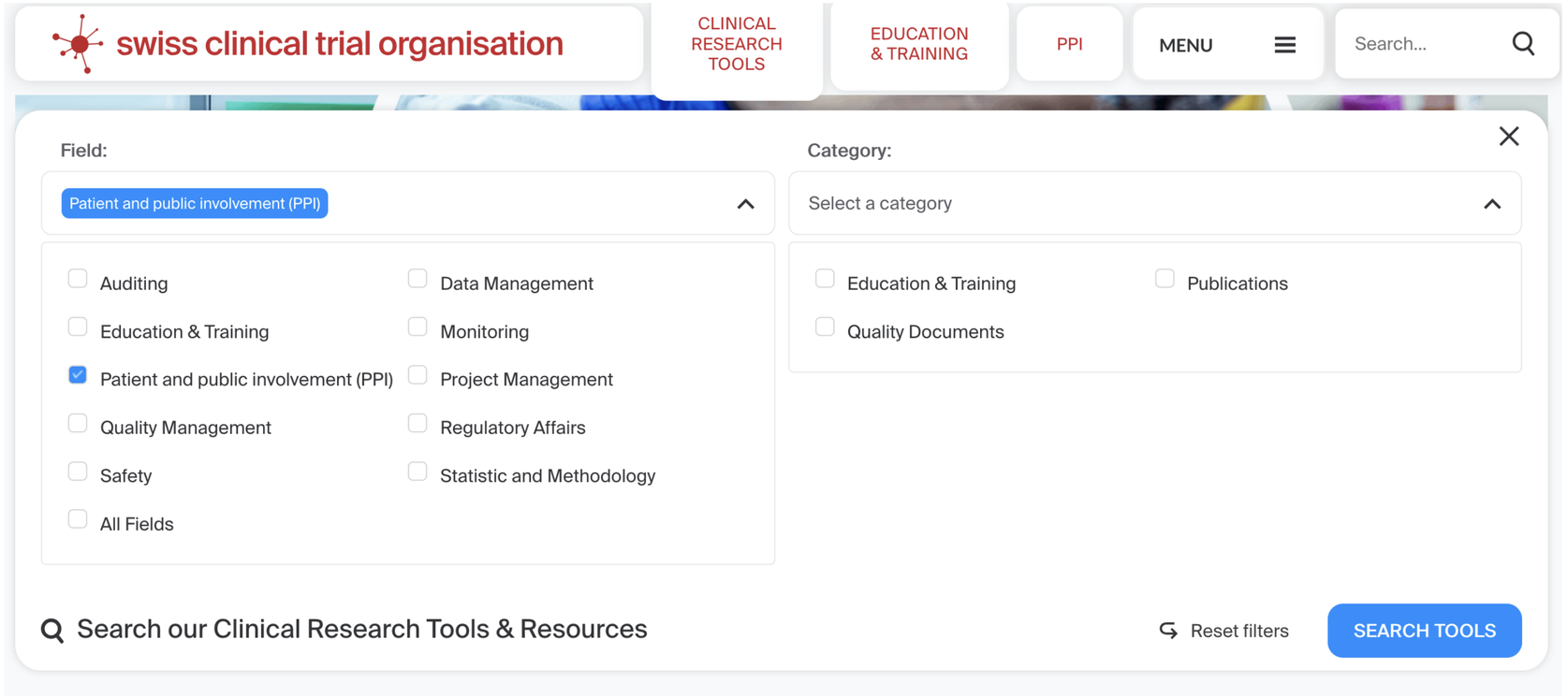
Academic clinical research infrastructure of national importance

The SCTO provides all the services to plan, conduct and analyse high-quality clinical research projects

- Pathology-unspecific → all therapeutic fields
- Supports all types of clinical research projects (clinical trials and data-driven / interventional and observational clinical research projects)
- Services are provided by the seven Clinical Research Centres (CRCs): 5 university hospitals, 2 cantonal hospitals
- Each CRC coordinates one of the eight SCTO Platforms focusing on one key area of clinical research: Auditing, Data Management, Education, Monitoring, Project Management, Regulatory Affairs, Safety, and

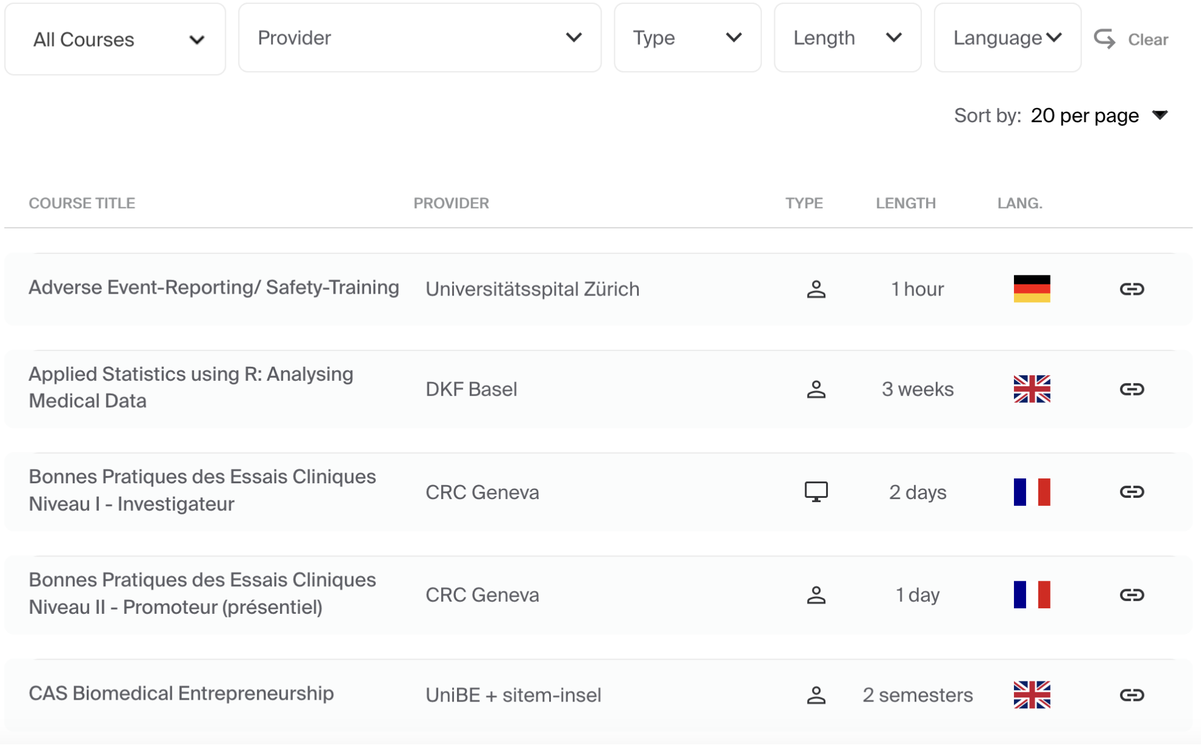
SCTO Tools & Resources Navigator

Visit our website and discover the SCTO Tools & Resources Navigator: https://www.scto.ch/clinical-research-tools/



Course Finder

Visit the SCTO course finder to discover courses for clinical researchers: https://www.scto.ch/education-and-training/clinical-research-training/



What is PPI?

Research being carried out '**with**' or '**by**' patients and members of the public rather than '**to**', '**about**' or '**for**' them.

Definition from UK Health Research Authority (NHS)

→ **No internationally harmonised definition yet**

https://www.hra.nhs.uk/

What is PPI?

Involvement

patients and members of the public are **actively involved/engaged** in clinical research projects as full partners

Participation

patients and members of the public **take part** in a clinical trial, usually by providing health data

Patients
as defined by EUPATI: *the public in general, individual patients, patient organisation representatives, caregivers, patient advocates, patient experts*

➽ ***PPI contributor(s)***

Why should PPI be integrated into research (1)

Today's research is tomorrow's medicine/therapy

- Patients are directly affected by the outcome of clinical research. Therefore, they should have an influence on it => **"nothing about us without us"**

Patient empowerment

- PPI supports the **empowerment** of patients and addresses their right to have a voice in clinical research.
- It increases their capacity to act on issues that they themselves define as important.

Accountability

- It has the potential to **democratise** the research process and make clinical research more **accountable**.

Transparency

- Academic clinical research is **financed by governmental/public funds**. PPI can help to make the funding more transparent.

Why should PPI be integrated into research/study (2)

Relevance:

- Identify research questions that matter most to patients/public
- Help prioritise research agenda

Recruitment/Retention

- Connect with appropriate patient community
- Advice on feasibility of study process

Relation/Transparency

- Disseminate study results to wider public

⇒The research is more likely to be designed and conducted in a way which is acceptable to the patient.

⇒ Involving the right people well can help to produce research which respects the rights, safety, dignity and wellbeing of participants.

How to find your PPI contributor(s)?

Our recommendations:

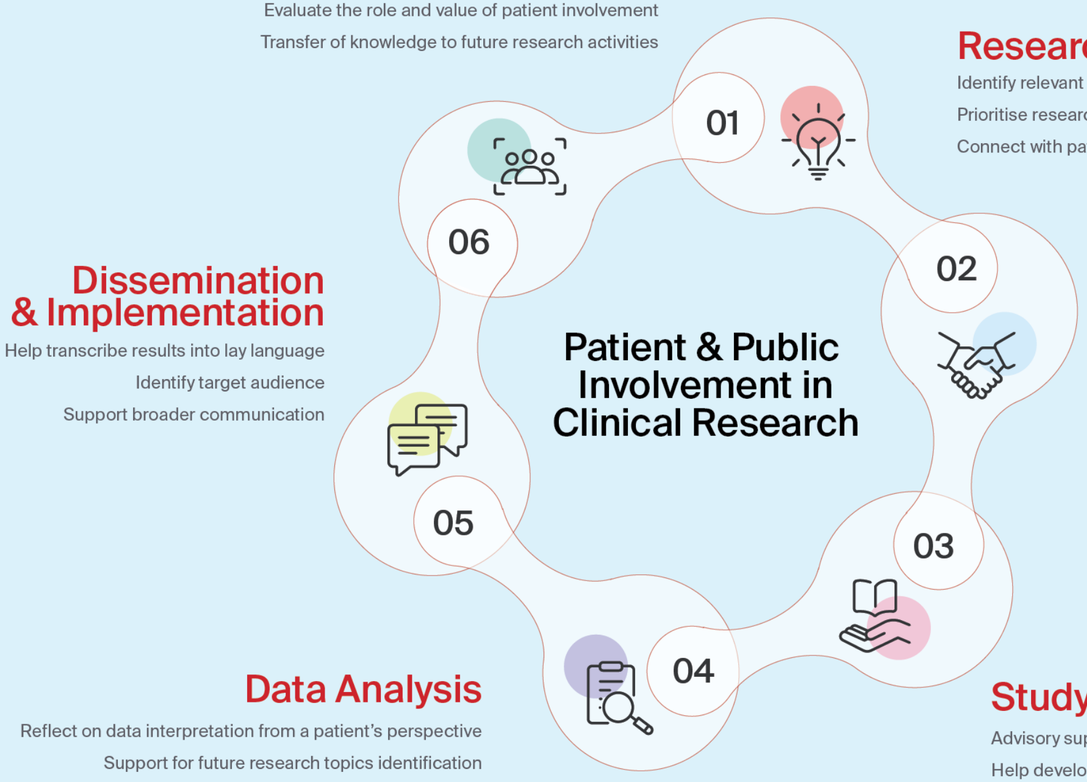
- Align internally
- Identify and contact relevant patient organisations
- Post a call for interest
- Contact your local Clinical Research Centre (CRC)
- Contact the SCTO and ask for support (ppi@scto.ch)

How to find your PPI contributor(s)?

Develop information material that

- Clearly explains your research project in lay language
- Describes the role of the PPI contributor(s)
- Specifies the knowledge/experience/skills your PPI contributor should bring
- Provides information about the amount of work/time required as well as on remuneration

Possibilites for PPI



Evaluation

Evaluate the role and value of patient involvement

Transfer of knowledge to future research activities

Research Questions

Identify relevant research questions or unmet medical needs

Prioritise research questions

Connect with patient groups

Dissemination & Implementation

Help transcribe results into lay language

Identify target audience

Support broader communication

Study Design & Funding

Propose outcome measures, relevant to patients

Support of patient-appropriate method development

Improve recruitment strategy

Data Analysis

Reflect on data interpretation from a patient's perspective

Support for future research topics identification

Study Management

Advisory support throughout the study lifecycle

Help develop clear patient-facing material

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Clinical Researchers

- Improve the **quality, relevance, and feasibility** of your research by involving patients and patient representatives
- Benefit from their insights to address **real needs** and enhance **recruitment, retention, and outcomes**
- Access **practical tools** and **training opportunities** within the SCTO Network to support meaningful PPI
- Explore examples from other organisations for **inspiration and guidance**
- Find approaches that work for your context; **there's no one-size-fits-all model** for PPI

Read more →

Patients and Public

- Discover how to **actively shape clini** representative
- Learn about opportunities to **join stu** your perspective
- Explore **SCTO Network training** tailo public
- Access **helpful resources** to better u clinical research and PPI

Read more →

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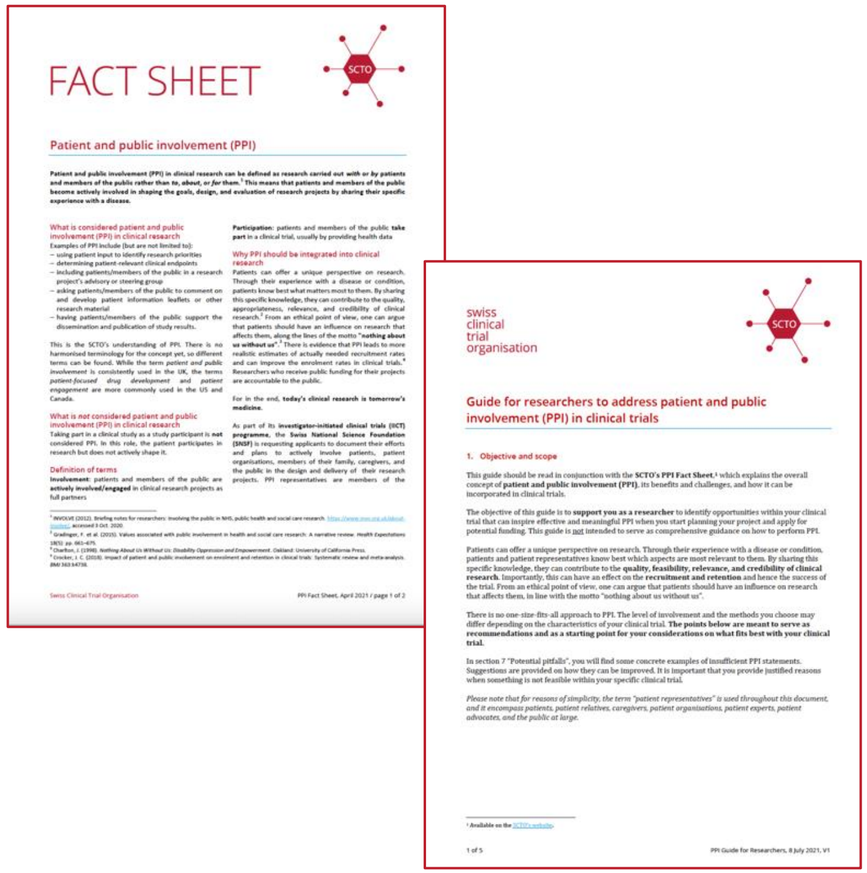
Implement PPI in Clinical Research

Make research more relevant and effective by involving patients and patient representatives. Their unique perspectives help address real needs, improve recruitment and outcomes, and ensure feasibility. Our practical tools can help researchers find the PPI approach that works best for the research project.

Resources for Clinical Researchers

- PPI Fact Sheet +
- Guide for Researchers to Address PPI in Clinical Trials +
- SCTO Remuneration Policy for PPI Activities +
- Participation Request for PPI Activities Template +
- Written Agreement for PPI Activities Template +
- Planning, Tracking, and Evaluating PPI Activities Template +
- Online Webinar | SNSF IICT 2026 application: How to successfully address the PPI requirements +

PPI resources (1)



FACT SHEET

Patient and public involvement (PPI)

Patient and public involvement (PPI) in clinical research can be defined as research carried out with or by patients and members of the public rather than to, about, or for them.[1] This means that patients and members of the public become actively involved in shaping the goals, design, and evaluation of research projects by sharing their specific experience with a disease.

What is considered patient and public involvement (PPI) in clinical research

Examples of PPI include (but are not limited to):
- using patient input to identify research priorities
- determining patient-relevant clinical endpoints
- including patients/members of the public in a research project's advisory or steering group
- asking patients/members of the public to comment on and develop patient information leaflets or other research material
- having patients/members of the public support the dissemination and publication of study results.

This is the SCTO's understanding of PPI. There is no harmonised terminology for the concept yet, so different terms can be found. While the term *patient and public involvement* is consistently used in the UK, the terms *patient-focused drug development* and *patient engagement* are more commonly used in the US and Canada.

What is *not* considered patient and public involvement (PPI) in clinical research

Taking part in a clinical study as a study participant is **not** considered PPI. In this role, the patient participates in research but does not actively shape it.

Definition of terms

Involvement: patients and members of the public are **actively involved/engaged** in clinical research projects as full partners

Participation: patients and members of the public **take part** in a clinical trial, usually by providing health data

Why PPI should be integrated into clinical research

Patients can offer a unique perspective on research. Through their experience with a disease or condition, patients know best what matters most to them. By sharing this specific knowledge, they can contribute to the quality, appropriateness, relevance, and credibility of clinical research.[2] From an ethical point of view, one can argue that patients should have an influence on research that affects them, along the lines of the motto "**nothing about us without us**".[3] There is evidence that PPI leads to more realistic estimates of actually needed recruitment rates and can improve the enrolment rates in clinical trials.[4] Researchers who receive public funding for their projects are accountable to the public.

For in the end, **today's clinical research is tomorrow's medicine.**

As part of its **investigator-initiated clinical trials (IICT) programme**, the **Swiss National Science Foundation (SNSF)** is requesting applicants to document their efforts and plans to actively involve patients,, patient organisations, members of their family, caregivers, and the public in the design and delivery of their research projects. PPI representatives are members of the

[1] INVOLVE (2012). Briefing notes for researchers: involving the public in NHS, public health and social care research. https://www.invo.org.uk/about-involve/, accessed 3 Oct. 2020
[2] Gradinger, F. et al. (2015). Values associated with public involvement in health and social care research: A narrative review. *Health Expectations* 18(5): pp. 661–675.
[3] Charlton, J. (1998). *Nothing About Us Without Us: Disability Oppression and Empowerment*. Oakland: University of California Press.
[4] Crocker, J. C. (2018). Impact of patient and public involvement on enrolment and retention in clinical trials: Systematic review and meta-analysis. *BMJ* 363:k4738.

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PPI Fact Sheet, April 2021 / page 1 of 2

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Guide for researchers to address patient and public involvement (PPI) in clinical trials

1. Objective and scope

This guide should be read in conjunction with the **SCTO's PPI Fact Sheet**,[1] which explains the overall concept of **patient and public involvement (PPI)**, its benefits and challenges, and how it can be incorporated in clinical trials.

The objective of this guide is to **support you as a researcher** to identify opportunities within your clinical trial that can inspire effective and meaningful PPI when you start planning your project and apply for potential funding. This guide is not intended to serve as comprehensive guidance on how to perform PPI.

Patients can offer a unique perspective on research. Through their experience with a disease or condition, patients and patient representatives know best which aspects are most relevant to them. By sharing this specific knowledge, they can contribute to the **quality, feasibility, relevance, and credibility of clinical research**. Importantly, this can have an effect on the **recruitment and retention** and hence the success of the trial. From an ethical point of view, one can argue that patients should have an influence on research that affects them, in line with the motto "nothing about us without us".

There is no one-size-fits-all approach to PPI. The level of involvement and the methods you choose may differ depending on the characteristics of your clinical trial. **The points below are meant to serve as recommendations and as a starting point for your considerations on what fits best with your clinical trial.**

In section 7 "Potential pitfalls", you will find some concrete examples of insufficient PPI statements. Suggestions are provided on how they can be improved. It is important that you provide justified reasons when something is not feasible within your specific clinical trial.

Please note that for reasons of simplicity, the term "patient representatives" is used throughout this document, and it encompass patients, patient relatives, caregivers, patient organisations, patient experts, patient advocates, and the public at large.

[1] Available on the SCTO's website.

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PPI Guide for Researchers, 8 July 2021, V1

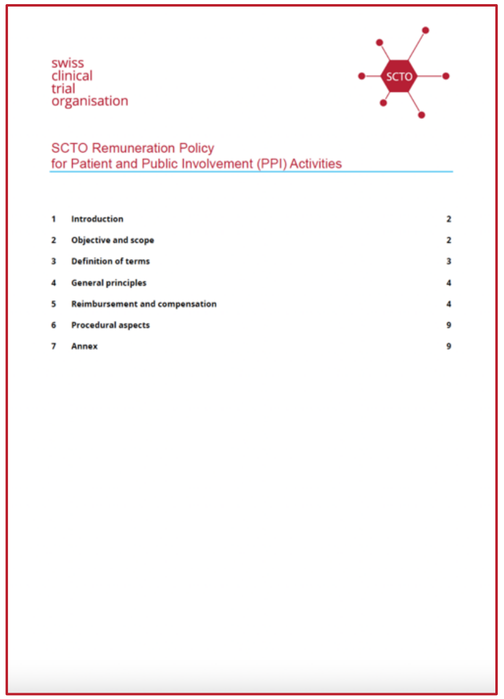
Fact Sheet

- ✓ overall concept of PPI
- ✓ benefit and challenges
- ✓ how it can be incorporated in clinical trials

Guide for researchers to address PPI in clinical trials

- ✓ **Objective:** support researchers to identify PPI opportunities that inspire effective and meaningful involvement of patients

PPI resources (2)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SCTO

SCTO Remuneration Policy
for Patient and Public Involvement (PPI) Activities

SCTO Remuneration Policy for PPI Activities

- To implement PPI in a sustainable way, the SCTO commits to remunerate PPI contributors

✓ Policy outlines SCTO's commitment for **reimbursement** (travel, accommodation) and **compensation** (PPI activities)

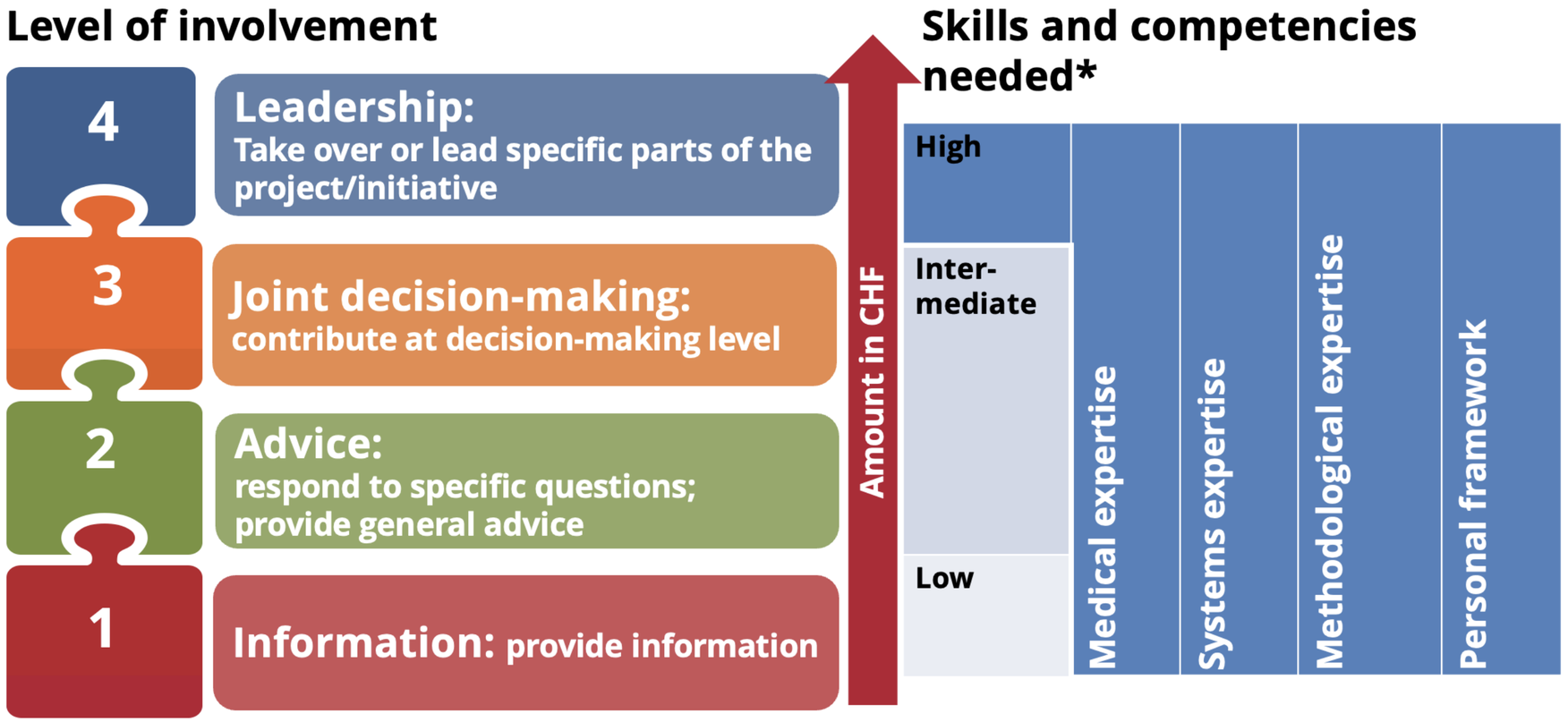
✓ **Fair** financial compensation informed by the principles of equity

✓ **Blended model** approach based on two criteria

- ✓ level of involvement
- ✓ skills/capacities needed for PPI activity

available in DE, FR, EN

Blended compensation model



Thank You

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